

How to decide whether to support public involvement in commercial projects



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Introduction

Public contributors are active across the health research sector in the United Kingdom, guiding priority setting, approving funding applications, sitting on ethics committees, advising academic teams and sometimes partnering in data collection, analysis and dissemination. They are motivated by a desire to see patient care improve and often make themselves vulnerable by sharing their own lived experience of illness for the benefit of others. This paper offers some questions that public contributors may wish to ask before deciding whether to get involved in research projects where commercial interests are in play.

Some pharmaceutical and healthcare device companies directly commission, manage and deliver health research. The evidence clearly shows that research can be more effective when public contributors help, and so some of the commercial organisations are courting patient groups and individual public contributors, seeking their help in running the research.

Goals are less easy to discern when the health research project is carried out as a partnership between academic, non-profit and commercial organisations. Sometimes a stream of research begins in the academic or non-profit sector and acquires public contributors who then find

themselves travelling with the developing project and into broader partnerships with commercial organisations. In these more subtle environments, it is vital that public contributors stop and consider whether they wish to become involved or remain involved.

There are reasons to steer clear of such arrangements, as well as reasons to be involved, and public contributors may wish to ask the following questions before signing up. Readers who want to find further evidence may wish to review the companion resource paper to this document¹.

Are you fit enough?

Some meetings are held at the premises of a pharmaceutical company where considerable efforts must be made to maintain hygiene standards so that the products are safe to use and so public contributors who are carrying infection risk should avoid them. Similarly, people whose experiences are so recent and powerful that are unable to move away and listen to others should probably not be involved at this time. Such experiences may include life-changing events such as bereavement or serious illness, some acute mental health crises or an ongoing complaint related to healthcare. Rigidly applied rules about such matters are unhelpful, but the general principle remains that the overriding goal of public contribution is to add value to a broader project rather than personal gain.

Does the company prioritise profit or patients?

Much government policy in the United Kingdom is based on the idea that the interests of clinicians, researchers and industry will converge to benefit the health of the nation. As business succeeds, so everyone's standard of living will improve, lifting the disadvantaged out of poverty and poor health. As a result of taking this view, some organisations that promote public involvement see no distinction between the non-profit and the commercial sector and promote unthinking participation.

In contrast, some pharmaceutical companies have shown themselves willing to deny treatment to patients in the race to maximise profit. Consequently, public contributors may be unwilling to engage unless they see evidence that the company prioritises patient care over callous profit.

Can you go everywhere?

Worries about patients being seduced into demanding a particular pharmaceutical product and so enhancing the profit of its manufacturer have led to the development of codes of practice. These entirely legitimate concerns have had unintended consequences, such as where companies deny patients access to their conferences and exclude them from any role that might influence the shape of the company itself. This restricted role, through which public contributors are confined to commenting on patient information sheets and receiving help with health education, is radically different from the coproduction approach that guides publicly funded research and healthcare provider organisations. In these latter bodies, public contributors are sitting on governance and strategic planning groups, staff appointment and quality assurance panels, investigatory and

¹ See <http://peterbates.org.uk/wp-content/uploads/2020/01/Public-involvement-in-commercial-projects-resource-paper.pdf>

disciplinary bodies. In short, public contributors are affecting the shape of the organisation, sharing power with the Boardroom and management team, participating in accountability structures at every decision-making point in the organisation. Not all of these things are happening everywhere yet, of course, but patient voices are heard in a growing number of places.

Public contributors who are invited to get involved with commercial organisations may want to know whether their role is to speak in many of these places, or whether it is confined to a narrow function which will simply deliver the defined research project more effectively and thus enhance the profit of the company.

Is the company exercising its corporate social responsibility?

Many commercial healthcare businesses are large enterprises that have a heavy footprint on the world. They may prioritise environmental sustainability or exploit the planet's natural resources. They may trade fairly with the developing world or pay survival wages to some and vast bonuses to others. They may share their skills through corporate volunteering or signal superficial virtue through cynical media stunts. The individual patient may have no alternative to using the company's product and so bolstering its profits, but public contributors have the freedom to choose whether to be involved or not.

Is the company listening?

Whether the opportunity to be involved lies in the clinical, academic, non-profit or commercial sectors, public contributors will have more confidence in the organisation that can show a track record of issues that were raised and then addressed, rather than raised and set aside. An example that combines this issue of listening with the previous question about corporate social responsibility is the equalities issue in the company's workforce. Public contributors may ask whether the company recruits disabled employees and makes reasonable adjustments to enable them to get and keep a job.

Is the company simply harvesting ideas and seeking kudos from a tokenistic consultation exercise in its research department or is it listening to challenges from public contributors through a creative, respectful partnership? If the company is not listening, then public contributors should feel free to walk away.

Can you speak freely?

A positive relationship between the commercial organisation and public contributors will mean that each will check the content of any press releases about the other before they go ahead and publish. This goes wrong when the public contributor is required to promote the interests of the company in exchange for participation or when they are silenced and unable to make any remark at all that might be construed as damaging for the company. It gets worse when patients are paid by the company to tell their poignant story in the mass media so that pressure is placed on the NHS to buy a certain drug. Patient organisations that receive funding from commercial healthcare organisations are especially vulnerable to these pressures. Public contributors will be courteous and respectful of

commercial interests but should retain their independent voice and reject any invitations to join the marketing department.

Are relevant accounts open to scrutiny?

Where commercial healthcare businesses provide funding or benefits in kind to patient organisations, this should be open to scrutiny. Some patient organisations try to manipulate their reputation by hiding these details, while pharmaceutical organisations might breach their regulations by trying to retain bargaining advantage and keep such arrangements private.

Patient organisations may receive funding support from commercial bodies but should not become unduly reliant upon one particular source as they might lose their independent voice or reputation. Public contributors can insist on openness on both sides of the relationship.

Are you getting fair market value?

In the volunteering sector, members of the public choose to give their time, skills and energy to projects that benefit the community, but they do not help commercial organisations realise a profit from their labour. Public contributors may feel it is wrong for shareholders to be making significant profits while they donate their expertise for little or no reward. Where payments are made, they should not be extravagant, but rather fair market value, comparable with the sums paid to other consultants used by the business.

Are procedures respectful?

Public contributors may feel unable to work, grateful for the chance to speak, and honoured to be invited. The procedures used to engage, select and recompense them should be based on dignity and respect, rather than exploiting these feelings. It should not be assumed that they are in receipt of welfare benefits or are likely to defraud the benefits agency or tax office. Perhaps they should only be offered vouchers or the opportunity to refuse payment if employees are given the same offer by the wages department. Travel arrangements should be made on their behalf and they should not be made to wait extended periods for reimbursement of out of pocket expenses.

Is intellectual property honoured?

Public contributors offer brilliant ideas that improve research, sharpen findings and enhance patient care, so own a share in the intellectual property arising during the research. As such, they should be able to play a part in the distribution of these ideas, receive credit for their work and object to their distortion or mutilation. Public contributors will want to be involved as co-authors of academic papers and posters, co-presenters at conferences and co-interviewees in news reports. If the commercial organisation is doing no more than harvesting intellectual property from anonymised patients, denying them access to their own data, delaying or suppressing its publication or publishing it in expensive journals rather than on Open Access websites, then this is not what most public contributors understand to be coproduction and they may leave the project or never join in the first place.